Testimony of Lisa M. Kenney to the Public Health Committee regarding House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants

February 6, 2009

Senator Harris, Representative Ritter, members of the Public Health Committee: Thank you for giving me the opportunity to speak to you today about House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants. I have a 15 year old daughter with CF. She was diagnosed as a newborn, in the hospital, by use of the newborn screening test. Within one month we had her first visit at a CF clinic and were treating her. Before we were contacted with the diagnosis she had been losing weight and struggling. Her pediatrician had no reason to suspect CF as there was no family history of this condition. If it weren't for the screening we might have spent precious time wondering and leaving her untreated. I assumed that all hospitals gave this test because we did not go to a big city hospital, and not until a few years ago did I learn that that was not the case. I am very thankful for the head start we were given treating our precious child. Today she is a healthy young woman with a few extra steps she needs to take in her day to remain so, but unless we tell anyone of her condition it is not obvious. She has had a few illnesses that were frightening to us, but she has never been hospitalized because of her CF and I believe that the time we saved diagnosing her may have been instrumental in her continued good health. The screening test is so simple and convenient and not even something that the parents are really aware of, so there is not reason not to do it and every reason to give a child a better chance to start a healthy life as soon as possible.

Thank you for your attention.